

# Young People and Chronic Illness: A more responsive healthcare world

**A professional doctorate submitted in partial fulfilment of the  
requirements for the degree of Doctor of Nursing**

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## **CERTIFICATE OF AUTHORSHIP/ORIGINALITY**

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

Signature of Candidate

A handwritten signature in black ink, consisting of stylized initials followed by a horizontal line.

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## ABSTRACT

There is extensive literature suggesting that, although most young people cope well and adjust to life with chronic illness, some young people develop poorer psychosocial health and functioning, and have an increased risk of psychopathology in adulthood. This area of concern to nurses working with these young people is poorly addressed in the literature, specifically, the literature about how young people with chronic illness are cared for from a psychosocial perspective, in an adult hospital, during the developmental period of adolescence. What literature does exist, focuses predominantly on the problems of improving treatment adherence, and provides little in the way of responsive service models or frameworks for nursing and interdisciplinary practice, to deal with underpinning psychosocial issues.

The aim of the work within this thesis is to extend knowledge about the psychosocial development and psychosocial health of young people with chronic illness. In particular, the focus is on how young people cope and adapt to living with chronic illness, and recommendations are made for clinical nurses to address the psychosocial needs of this group. The work of my professional doctorate emerged out of, is grounded within, clinical practice, and operates from the scope of experience of myself as a Registered Nurse, a Clinical Nurse Specialist, and as a Clinical Nurse Consultant.

The thesis has three components: first, a comprehensive analysis of the clinical situation that is at the centre of this thesis, and an associated literature review; second, an empirical research study focusing on one aspect of this complex situation; and a final, theoretical analysis of the healthcare world that young people with chronic illness experience, and of the professional lives of nurses. The clinical situation is presented as a reflective analysis of a clinical problem from multiple perspectives, and is followed by a review of relevant literature. The empirical study investigates the psychosocial functioning and treatment adherence of 85 young people aged 12-24 years in an adult hospital. The findings identify potential areas of difficulty in psychosocial functioning for some young people with chronic illness, suggesting that there is a subgroup facing significant challenges in coping with the effects of illness in their day-to-day lives. The third aspect, the theoretical component, builds upon the findings of the empirical study and examines the responsiveness of the healthcare world in relation to the needs of young people with chronic illness, and the place of nursing practice and clinical

leadership in addressing these needs. Clinical nursing leadership and clinical leadership activities are identified as being necessary at each level of this healthcare world. This leadership will ensure responsive nursing practice, the effective contribution of nursing skills within interdisciplinary teams and responsive policy reform, in order to optimise psychosocial outcomes for young people with chronic illness in an adult hospital.

Ecological Systems Theory (EST) provides the framework for the analysis of the healthcare world. The analysis revealed global dilemmas in how to sustain the provision of ethical, fiscally responsible, and clinically effective care to increasing numbers of chronically ill young people. The theoretical analysis facilitates the identification of potential ways that nursing can use a global perspective to plan services and to investigate the development of a coping framework for nursing interventions; and it highlights the crucial role of psychosocial developmental mastery in the formation of coping skills. The addition of Erikson's theory of psychosocial development complements EST by deepening the analysis of the internal world of the young people. The analysis draws on case studies to identify psychosocial risks, and points to several ways in which the clinical care of young people may facilitate developmental mastery; which I argue sits at the heart of coping and adaptation to illness.

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